

The Ying and Yang of Parkinson's

Parkinson's is both predictable and whimsical, observes IAN MURRAY.

Consider PETE:

He was diagnosed with Parkinson's at 49, some 11 years ago, but is still living an active life. Recently he wrote to a friend telling of his activities this year. Here are some of the highlights:

"Spent five days travelling with a mate in a small duck punt, 100kms down The Murray, from Tocumwal to Yarrowonga; Trained to become a CFA volunteer, and with my truck license, I regularly drive the fire tanker. (My fire captain is aware of my condition, but has noted I'm one of the more competent drivers); Harvested wood for winter warmth, using a chainsaw, mechanical log splitter, trailer and lots of heavy energy; Spent 11pm-2am rescuing a cow recently calved but down with milk fever. Searched around the steep mountain paddocks in the dark for the calf, and finally found and returned it to its rescued mother; Replaced 60m of fence for a friend where a gravel truck had left the road and rolled into his paddocks; L lectured at local College Campus on soils, with respect to Whole Farm Planning; Built a storage area/studio for my wife's soap-making cottage craft, and supported her at craft market stalls; Conducted out-of-sessions court hearings as a Bail Justice (usually being called in the middle of the night and occasionally to a police station 40 minutes drive away); Made things out of wood, including a table for 8 and a summerhouse in the garden; Attended *The Questings'* fortnightly breakfasts, a men's group that has met and supported each other for 14 years; Attended my weekly creative writing course; Flew to Sydney for my father's birthday; Pursued bureaucrats and medical personnel regarding recompense for a work injury; Continued to mow the lawns, do regular shopping and cooking."

And, Pete is planning future holidays touring Australia as a grey nomad.

On the other hand, consider PAT:

Also diagnosed with Parkinson's in his late 40s, nearly 12 years ago.

He cannot walk but only shuffles in tiny little steps. His balance is poor and moving across the room for more than a few metres takes real focus and determination. At night he finds it difficult to even turn over in bed.

His bladder sphincter seems to be weakening, the need to have a leak can be quite urgent. Muscular strength is waning and he more often needs the jar opening tool to access the jam. Pat needs to

take his medication at least 30 minutes before getting out of bed in the morning. He is regularly thwarted in daily activities by the inability to do tasks requiring dexterity or strength. He is embarrassed by dyskinesia - jerky movements that are a side effect of his medication. He becomes tired of fighting the disability and considers just giving in and retiring to the immobility of a comfy chair. He worries about the pressure his condition is placing on his wife, and worries about her worrying about the future.

At times, Pat wonders whether he will just fade into paralyzed indignity or head out to sea in a small boat with a handful of sleeping pills and a chisel to punch a hole in the bottom. He thinks it might be easier to become a hermit and thus avoid all future social discomfort. He is sad that his grandchildren won't have memories of exciting camping and fishing trip with Grandpa.

Two similar scenarios, two imprints of Parkinson's upon a life with radically different lifestyle effects. I feel glad for Pete and sad for Pat. I can identify with Pete but just don't know how it would be to be Pat. His situation is less familiar and I'm not sure how he would feel and function.

And that is my identity confusion, for they are both me: I am Pete when my medication has cut in and I'm switched "ON", and I'm Pat when my medication has been used up, or when the next tablets have not cut in, and I'm switched "OFF".

So, I don't know how to respond to my life and plan into the future. Should I withdraw from the volunteer work as a fire fighter and Bail Justice in case my disability may unpredictably hurt others? There is no evidence of that so far.

Should we leave the farm and move into easier, town-living or would that be like giving up and hasten the downward slide? I would love this hilltop to be my nursing home right until I fall off my perch, but would it be easier for my wife Glyn if we moved into town before I disappear? Will stem cell research or new surgical procedures come in time and restore me to a normal old age?

At times I feel a very Muddle Headed Wombat.